

I. OVERVIEW OF THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

This chapter outlines the key features of the Older Americans Act (OAA) and specifically Title III, Part E, the National Family Caregiver Support Program and Title VI, Part C, the Native American Caregiver Support Program. Although authorized separately under Title III and Title VI, these two components make up the National Family Caregivers Support Program (NFCSP). This chapter provides a brief description of the program; a discussion of the new client population, the program's goals, funding, and program policies; as well as opportunities and challenges for the network.

OLDER AMERICANS ACT CONTEXT

The OAA of 1965 established the Administration on Aging (AoA) within what is now called the Department of Health and Human Services (DHHS). When originally passed, the OAA authorized grants to State Units on Aging (SUAs) for community planning and services programs. Later amendments to Title III of the OAA, "Grants For State for State and Community Programs on Aging", authorized Area Agencies on Aging (AAAs) for planning and funding of services at the sub-state level. Under Title III, specific service programs include:

- Congregate and homebound nutrition programs for the elderly;
- Health promotion and disease prevention activities;
- In-home services for frail elders;
- Support services, such as transportation; and
- Services that protect the rights of older persons, such as the Long-Term Care (LTC) Ombudsman Program.

The OAA also authorized grants under Title VI to be awarded directly to Indian tribal organizations and organizations representing Native Hawaiians. Service programs are similar to Title III: e.g. congregate and homebound nutrition programs, information and assistance, transportation services, and services that protect the rights of older persons.

The NFCSP builds on these OAA programs and a number of other initiatives during the past 15 years:

- Research sponsored by AoA, the National Institute on Aging (NIA), and others that focused on demonstrating the effectiveness of providing support services to caregivers;
- State-funded caregiver support programs created in the 1980s and 1990s as a response to the growing numbers and needs of caregivers serving an expanding population of older persons wanting to remain in the community; and
- Advocacy by organizations representing caregivers, such as the Alzheimer's Association and the Family Caregiver Alliance (FCA).

The NFCSP acknowledges and encourages the vital role caregivers play in the country's home- and community-based services (HCBS) system. The program seeks to support caregivers in a coordinated and responsive manner.

NFCSP IN BRIEF

Title III-E of the OAA authorized the NFCSP, and Title VI-C authorized the Native American Caregiver Support Program. These amendments (Public Law 106 – 501), both passed in 2000, constitute the first major nationwide program initiatives under the OAA since the 1970s.

Family caregivers have always been the mainstay underpinning LTC for older persons in this country. In 1994 among non-institutionalized persons needing assistance with activities of daily living (ADLs), about two-thirds depended solely on family and friends, and another one-fourth supplemented family care with services from paid providers. Only a little more than 5 percent relied exclusively on paid services.¹

The program calls for all states and tribes, working in partnership with AAAs and local community-service providers, to offer five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;
- Respite care to temporarily relieve caregivers from their responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

NFCSP Service Components

1. Information
2. Assistance
3. Individual counseling, support groups, and training
4. Respite
5. Supplemental services

AoA, in developing the program design for the NFCSP legislation, included these service components based on the preponderance of research evidence that indicated they would best meet the range of caregivers' needs and provide the necessary flexibility through the supplemental service category. AoA also drew on the experience of successful state programs, such as those in Pennsylvania, California, and Wisconsin, to identify the services that might constitute an effective multifaceted system of support services for caregivers.

NEW CLIENT POPULATION

The network has always been involved with both the care recipient and caregivers, but now it is charged with addressing caregiver needs explicitly. The OAA identified the following specific caregiver populations:

- Family caregivers of older adults, which encompasses non-relatives.
- Grandparents and relative caregivers of children 18 years of age and younger (including grandparents who are sole caregivers of grandchildren and children who are affected by

¹ Liu, K., Manton, K.G., and Aragon, C. (2000 January). *Changes in Home Care Use by Older People with Disabilities: 1982–1994*. Washington, DC: AARP Public Policy Institute.

mental retardation or who have developmental disabilities [MR/DD], although disability of the grandchild is not required). The caregivers must be a grandparent or step-grandparent of a child or a relative of a child by blood or marriage, be over age 60, live with the child, act as the primary caregiver of the child, and have a legal relationship to the child or raise the child informally.

NFCSP TARGET POPULATION REQUIREMENTS		
Caring for:	Any Informal Caregiver	Family Caregivers Age 60+
Priority Title III-E and Title VI-C Populations:	Older Adults Those providing care to older individuals in the greatest social or economic need with particular attention to low- income individuals	Children < age 18 and older adults Older individuals providing care to children ≤ age 18 with MR/DD and older adults with MR/DD

The statute also requires states to give priority consideration to persons in greatest social and economic need (with particular attention to low-income older individuals and older relatives caring for children or older adults with MR/DD). The term “family caregiver” is used generically in this Resource Guide to reflect the legislative language, including any informal caregiver of older adults and grandparents or other relative caregivers over age 60. The NFCSP was enacted as an effort to meet the needs of this segment of the caregiver population. Expansions to the population covered by the OAA only can be effected through an amendment to the Act.

PROGRAM GOALS

The OAA calls for all states and tribes, working in partnership with AAAs and local service providers, to develop multifaceted systems of support services for family caregivers, including information; assistance; individual counseling, support groups and training; respite; and supplemental services. AoA envisions that each of the five service components ultimately will become available to caregivers in every state. Like other OAA services, the program is expected to leverage existing resources to best serve the new target population. It also is designed to stimulate development of a multifaceted system that spans and integrates OAA services and other relevant programs.

- Assistant Secretary Josefina Carbonell, in her opening statement during The National Family Caregiver Support Program: From Enactment to Action conference, elaborated on her vision of the program, specifying some features she hopes to see emphasized, including:
- Creation of optimum flexibility and choices for consumers;
- Partnering with and improving access to faith-based and other community-based providers to enhance support for older Americans and their families;
- Renewal of our focus on intergenerational care; and
- Increasing access so every American will know about the NFCSP, particularly disadvantaged and hard-to-reach families.

Assistant Secretary Carbonell also discussed important implementation strategies, urging the aging network to emphasize *family* services, communicate directly with caregivers, and learn from other programs while recognizing that every state, community, and family is different.

FUNDING

Congress appropriated \$125 million for Fiscal Year 2001 and \$141.5 million for Fiscal Year 2002 for the NFCSP. In Fiscal Year 2001, SUAs received the greatest proportion of these funds (\$113 million), allocated through a congressionally mandated formula based on a proportionate share of the over-70 population, while providing a minimum to each state. Another portion, approximately \$5 million in Fiscal Year 2001, supported grants to Indian Tribal Organizations (ITOs). The remainder of the funds go to National Innovation Program, competitive innovation grants and activities of national significance for program evaluation, training, technical assistance, and research. (See *Appendix B* for a list of Fiscal Year 2001 Native Americans Elders Caregiver Grants and National Innovation Programs).

PROGRAM POLICIES

Appendix A provides relevant documents related to program policies, including the NFCSP legislation, the AoA Program Instruction 01-02, and the Interim Reporting Guidelines. Regulations for the reauthorized OAA, including the new NFCSP, will be developed after AoA completes a series of “Listening Sessions” to solicit input from the field.

CHALLENGES AND OPPORTUNITIES FOR THE NETWORK

Implementing the NFCSP provides the aging network with both potentially difficult challenges and exciting opportunities. Among these are:

- Integrating the NFCSP with other OAA activities;
- Developing multi-faceted service systems for caregivers in collaboration with agencies within and outside the network;
- Tailoring programs to the diverse caregiver populations that exist in all jurisdictions;
- Focusing on the needs of caregivers as well as those of care recipients and, to the maximum degree possible, integrating these efforts;
- Building flexible and innovative approaches to providing caregiver support services; and
- Developing planning information based on the characteristics and needs of caregivers, and mechanisms for conceptualizing program effectiveness and outcome measures.

This Resource Guide cannot fully address all the issues that arise in the implementation of the new program. It can, however, provide useful information, based on established research and early practice experience, which can assist network agencies as they attempt to resolve these issues.

As a brief overview of the rest of the Guide, listed below are thumbnail summaries of the chapters that follow. Readers are urged to refer to chapters that might be most helpful in meeting their implementation needs.

Chapter II: Roles of the Aging Network describes the ongoing roles and responsibilities of the aging network, including policy development, technical assistance, advocacy, networking, service provision, and reporting, as well as how the NFCSP fits into these roles and responsibilities.

Chapter III: Profile of Family Caregivers examines data on caregiver characteristics and needs, including those of grandparents and relative caregivers of children.

Chapter IV: Systems Development provides a framework for placing the NFCSP within the larger context of the long-term care system and possible strategies for developing partnership opportunities with other agencies.

Chapter V: Program Effectiveness presents mechanisms for conceptualizing program effectiveness in relation to caregiver services and considerations for developing useful outcome measures.

Chapter VI: Working with Families and Other Caregivers explores how the network might move from focusing almost exclusively on care recipients to considering caregiver needs.

Chapter VII: NFCSP Service Components discusses each of the five major service components specified by the NFCSP, providing service descriptions, program examples, and discussion of implementation issues.

Chapter VIII: Designing the NFSCP in the Context of Diverse Caregiver Populations examines the considerations in serving diverse target populations distinguished by: 1) demographic factors, e.g., ethnicity, race, and culture; 2) special caregiver circumstances, e.g. grandparents raising children; and 3) environmental conditions, e.g., working caregivers, rural caregivers, and long-distance caregivers.

Chapter IX: Nontraditional Approaches highlights several innovative strategies and approaches to enhance caregiver support through: 1) consumer direction, 2) caregiver self-advocacy, 3) volunteer models, and 4) technology applications.